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ON BEHALF OF THE
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AND THE
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## REGARDING FISCAL YEAR 2010 APPROPRIATIONS FOR THE NATIONAL INSTITUTES OF HEALTH'S NATIONAL LIBRARY OF MEDICINE

SUBMITTED TO THE
HOUSE COMMITTEE ON APPROPRIATION'S SUBCOMMITTEE ON
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED
AGENCIES

WEDNESDAY, MARCH 18, 2009, 10:00AM

#### **SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2010:**

- 1) CONTINUE THE COMMITMENT TO PROVIDING THE NATIONAL INSTITUTES OF HEALTH (NIH) AND THE NATIONAL LIBRARY OF MEDICINE (NLM) WITH MEANINGFUL FUNDING INCREASES ON AN ANNUAL BASIS.
- 2) CONTINUE TO SUPPORT AND DEFEND THE NIH'S PUBLIC ACCESS POLICY, WHICH REQUIRES THAT ALL FINAL, PEER-REVIEWED MANUSCRIPTS ARE MADE AVAILABLE THROUGH NLM'S PUBMED CENTRAL DATABASE WITHIN 12 MONTHS OF PUBLICATION.
- 3) CONTINUE TO SUPPORT THE MEDICAL LIBRARY COMMUNITY'S IMPORTANT ROLE IN NLM'S OUTREACH, TELEMEDICINE, DISASTER PREPAREDNESS AND HEALTH INFORMATION TECHNOLOGY (HEALTH IT) INITIATIVES.

On behalf of the Medical Library Association (MLA) and the Association of Academic Health Sciences Libraries (AAHSL), thank you for the opportunity to present testimony regarding FY 2010 appropriations for the National Library of Medicine (NLM).

MLA is a nonprofit, educational organization with more than 4,000 health sciences information professional members worldwide. Founded in 1898, MLA provides lifelong educational opportunities, supports a knowledgebase of health information research, and works with a global network of partners to promote the importance of quality information for improved health to the health care community and the public.

AAHSL is comprised of the directors of the libraries of 142 accredited American and Canadian medical schools belonging to the Association of American Medical Colleges (AAMC). AAHSL's goals are to promote excellence in academic health sciences libraries and to ensure that the next generation of health professionals is trained in information-seeking skills that enhance the quality of healthcare delivery.

Together, MLA and AAHSL address health information issues and legislative matters of importance through a joint legislative task force and a Government Relations Committee.

#### 1) THE IMPORTANCE OF ANNUAL FUNDING INCREASES FOR NLM.

I thank the Committee for its leadership and hard work on the *American Recovery and Reinvestment Act of 2009* (P.L. 111-5), the economic stimulus package. As you know, the important mission of NIH and the important role that NLM plays in fulfilling that mission were hampered by past-years of near level funding. The investment in NIH and NLM provided by the stimulus package will not only create meaningful employment opportunities, it will also revitalize NLM's programs, which are focused on improving the public health.

We are pleased that the recently-passed FY 2009 Omnibus Appropriations package contains funding increases for NIH and NLM that will bolster their baseline budgets. We hope that this funding is an indication of the Subcommittee's intention to provide annual, meaningful increases for NIH and NLM in the coming years.

I am confident that the recovery funding and the FY 2009 budget increases will stimulate the economy, stimulate biomedical research, and in the case of NLM, improve the dissemination of health information to researchers, practitioners, and the general public. Moving forward, it will be critical to provide NIH's baseline budget with the funding increases necessary to allow the short-term growth generated by the stimulus to become a long-term investment towards improved public health through bolstered health information programs.

#### BUILDING AND FACILITY NEEDS

NLM has had tremendous growth in its basic functions related to the acquisition, organization and preservation of an ever-expanding collection of biomedical literature. It also has been assigned a growing set of set of responsibilities related to the collection, management, and dissemination genomic information, clinical trials information, and disaster preparedness and response. As a result, NLM faces a serious shortage of space,

for staff, library materials, and information systems. Digital archiving—once thought to be a solution to the problem of housing physical collections—has only added to the challenge, as materials must often be stored in multiple formats (physical and digital) and as new digital resources demand increasing amounts of storage space. As a result, the space needed for computing facilities has also grown. In order for NLM to continue its mission as the world's premier biomedical library, a new facility is urgently needed. The NLM Board of Regents has assigned the highest priority to supporting the acquisition of a new facility. Further, Senate Report 108-345 that accompanied the FY 2005 appropriations bill acknowledged that the design for the new research facility at NLM had been completed, and the Committee urged NIH to assign a high priority to this construction project so that the information-handling capabilities and biomedical research are not jeopardized.

#### THE GROWING DEMAND FOR NLM'S BASIC SERVICES

As the world's foremost digital library and knowledge repository in the health sciences, NLM provides the critical infrastructure in the form of data repositories and integrated services such as GenBank and PubMed that are helping to revolutionize medicine and advance science to the next important era—individualized medicine based on an individual's unique genetic differences.

NLM's clinical trials database, ClinicalTrials.gov, which was launched in February of 2000 and lists registration information on more than 70,000 U.S. and international trials for a wide range of diseases, also now serves as a repository for summary results information. The expanded system serves not only as a free but invaluable resource for patients and families who are interested in participating in trials of new treatments for a wide range of diseases and conditions, but also as an important source of information for clinicians interested in understanding new treatments and for those involved in evidence-based medicine and comparative effectiveness research.

As the world's largest and most comprehensive medical library, services based on NLM's traditional and electronic collections continue to steadily increase each year. These collections stand at more than 11.4 million items-books, journals, technical reports, manuscripts, microfilms, photographs and images. By selecting, organizing and ensuring permanent access to health science information in all formats, NLM is ensuring the availability of this information for future generations, making it accessible to all Americans, irrespective of geography or ability to pay, and ensuring that each citizen can make the best, most informed decisions about their healthcare. Without NLM our nation's medical libraries would be unable to provide the quality information services that our nation's health professionals, educators, researchers and patients have all come to expect.

#### 2) DEFEND PUBLIC ACCESS

The Appropriations Committee has shown unprecedented foresight and leadership by using the annual spending bills as the vehicle to establish a public access policy at the NIH. The current policy requires that all NIH-funded researchers deposit their final, peer-reviewed manuscripts in NLM's PubMed Central database within 12 months of publication. This policy will not only help NIH better manage its portfolio of research, but will contribute to the development of a biomedical informatics infrastructure that will stimulate further discovery by enabling a much greater and tighter interlinking of

information from NLM's wide-ranging set of databases. It also contributes to outreach initiatives by providing much-needed access to health literature to those without direct access to medical libraries. While the FY 2009 omnibus package made this policy permanent moving forward, challenges remain and we urge the Subcommittee to continue to defend this policy.

### 3) SUPPORT AND ENCOURAGE NLM PARTNERSHIPS WITH THE MEDICAL LIBRARY COMMUNITY.

#### Outreach and Education

NLM's outreach programs are of particular interest to both MLA and AAHSL. These activities are designed to educate medical librarians, health professionals and the general public about NLM's services. NLM has taken a leadership role in promoting educational outreach aimed at public libraries, secondary schools, senior centers and other consumer-based settings. Furthermore, NLM's emphasis on outreach to underserved populations assists the effort to reduce health disparities among large sections of the American public. One example of NLM's leadership is the "Partners in Information Access" program, which is designed to improve the access of local public health officials to information needed to prevent, identify and respond to public health threats. With nearly 6,000 members in communities across the country, the National Network of Libraries of Medicine (NNLM) is well positioned to ensure that every public health worker has electronic health information services that can protect the public's health.

With help from Congress, NLM, NIH and the Friends of NLM, launched *NIH MedlinePlus* Magazine in September 2006. This quarterly publication is distributed in doctors' waiting rooms, and provides the public with access to high quality, easily understood health information. Collaborating with the National Alliance for Hispanic Health, a Spanish version is now available, *NIH MedlinePlus Salud*. NLM also continues to work with medical librarians and health professionals to encourage doctors to provide MedlinePlus "information prescriptions" to their patients. This initiative also encourages genetics counselors to prescribe the use of NLM's Genetic Home Reference website.

"Go Local" is another exciting service that engages health sciences libraries and other local and state agencies in the creation of Web sites that link from MedlinePlus to relevant information on local pharmacies, hospitals, doctors, nursing homes, and other health and social services. In Iowa, for example, University of Iowa librarians developed an Iowa Go Local site that enables users to find local health resources by Iowa county or city. It allows Iowa citizens to link directly from a MedlinePlus health topic, for example asthma, to local services, such as clinics, pulmonary specialists, and support groups in the geographic area selected. By collecting such information in one place, Go Local also provides a platform for enhancing access to the information needed to prepare for and respond to disasters and emergencies.

MLA and AAHSL applaud the success of NLM's outreach initiatives, particularly those initiatives that reach out to medical libraries and health consumers. We ask the Committee to encourage NLM to continue to coordinate its outreach activities with the medical library community in FY 2010.

#### EMERGENCY PREPAREDNESS AND RESPONSE

MLA and AAHSL are pleased that NLM has established a Disaster Information Management Research Center to expand NLM's capacity to support disaster response and management initiatives, as recommended in the NLM Board of Regents Long Range Plan for 2006-2016. We ask the Subcommittee to show its support for this initiative, which has a major objective of ensuring continuous access to health information and effective use of libraries and librarians when disasters occur. Following Hurricane Katrina, for example, NLM worked with health sciences libraries across the country to provide health professionals and the public with access to needed health and environmental information by: 1) quickly compiling web pages on toxic chemicals and environmental concerns, 2) rapidly providing funds, computers and communication services to assist librarians in the field who were restoring health information services to displaced clinicians and patients and 3) rerouting interlibrary loan requests from the afflicted regions through the NNLM. Presently, libraries are a significant, but underutilized resource for community disaster planning and management efforts, which NLM can help to deploy. With assistance from its National Network of Libraries of Medicine, NLM is working with health sciences libraries to develop continuity of operations and backup plans and is exploring the role that specially trained librarians disaster information specialists – can play in providing information services to emergency personnel during a crisis. MLA and AAHSL see a clear role for NLM and the National Network of Libraries of Medicine in the nation's disaster preparedness and response activities.

#### **HEALTH IT AND BIOINFORMATICS**

NLM has played a pivotal role in creating and nurturing the field of biomedical informatics. Not only has NLM developed key biomedical databases, but for nearly 35 years, NLM has supported informatics research and training and the application of advanced computing and informatics to biomedical research and healthcare delivery including a variety of telemedicine projects. Many of today's informatics leaders are graduates of NLM-funded informatics research programs at universities across the country. Many of the country's exemplary electronic health record systems benefited from NLM grant support.

A leader in supporting, licensing, developing and disseminating standard clinical terminologies for free US-wide use (e.g., SNOMED), NLM works closely with the Office of the National Coordinator for Health Information Technology (ONCHIT) to promote the adoption of interoperable electronic records.

MLA and AAHSL encourage the Subcommittee to continue its strong support of NLM's medical informatics and genomic science initiatives, at a point when the linking of clinical and genetic data holds increasing promise for enhancing the diagnosis and treatment of disease. MLA and AAHSL also support health information technology initiatives in ONCHIT and the Agency for Healthcare Research and Quality that build upon initiatives housed at NLM.

Thank you for the opportunity to present the views of the medical library community.